

IS IT LEGAL?
IS IT MORAL?
IS IT ETHICAL?

What's the difference
and why should Cancer
Registrars care?

Why Ethics Now?

1. Ethics necessary element to being a professional

- ▶ Cancer registrars want recognition, professional status—survey results
- ▶ Higher education=higher salaries
- ▶ Higher ethical standards=higher respect
- ▶ Need self-governing, self-disciplining

Why Ethics Now?

2. Ethics is a 'hot' topic

- ▶ Media full of ethical failures—Medicare fraud, insider trading, cheating on tests
- ▶ Universities, business schools now have 'Centers for Ethics'

Ethics in Federal Government

- ▶ President Nixon resigned 1974 for lying
- ▶ If President could lie and cheat, then federal government also could not be trusted.
- ▶ 1978 Congress passes 'ethics' legislation
- ▶ Now more than 100 directors of ethics in every government agency

Ethics in State Governments

- ▶ New Jersey designed to be weak
- ▶ Missouri and Virginia ineffective
- ▶ Wisconsin strong and effective
- ▶ Alabama ethics commission not afraid to take on the governor, if necessary

Laurie DiMauro

Ethics in Business

- ▶ Jimmy Stewart (It's a Wonderful Life) vs. Ken Lay of Enron controversy
- ▶ Tobacco industry executives hid smoking dangers until lawsuits forced statements
- ▶ Enron and WorldCom lied about company finances and cheated their employees and shareholders.

New Ethical Questions re: Scientific Advances

- ▶ Cloning, stem cell research
- ▶ Euthanasia, transplant organ priority
- ▶ Animal to human transplants
- ▶ Surrogate motherhood
- ▶ Postmenopausal motherhood
- ▶ Genetic engineering

Ethics On Our Desks And In Our Computers

- ▶ Information technology issues
- ▶ Privacy, security, and accuracy=serious ethical concerns
- ▶ 39 healthcare workers at NY hospital facing suspension for inappropriately accessing medical records of 7 yr old abused child.

Ethics in School

- ▶ 24,000 high school students surveyed re: previous 12 months
- ▶ 66% had cheated on a test
- ▶ 25% had stolen from a store
- ▶ 92% satisfied with their own ethics and character

Laws, Morals, Ethics

- ▶ To live with other people, we must consider their rights as well as protect our own rights.
- ▶ Morals, laws, and ethics help us do that
- ▶ All attempt to distinguish right from wrong
- ▶ To influence and control human behavior

Morals

- ▶ Beliefs about behavior that develop over the years by various groups of people
- ▶ Enforced by 'losing face' or being considered sinful, embarrassment, loss of reputation

Laws

- ▶ Morals can differ according to culture and religion, laws enacted that would be applicable for all people in a society
- ▶ May be nothing 'immoral' in exceeding a speed limit but the law acts as a protection for yourself and others.
- ▶ May be same as a moral belief, 'thou shall not steal', but has a secular punishment

Ethics

- ▶ Actions performed by professionals not necessarily under moral or legal jurisdiction
- ▶ Lying about being a CTR may not be illegal or immoral, but certainly unethical
- ▶ Ethics developed so public and peers can trust a profession's members.
- ▶ Self governance goes beyond following moral standards and obeying laws

10 Commandments

- ▶ List of moral and religious imperatives
- ▶ Written by God on stone, given to Moses
- ▶ In first 5 books of Old Testament, 1500 to 1000 BC
- ▶ 'Honor your mother and father, so your days may be long....'
- ▶ Instruction for moral behavior but not legally required today

Ethics

- ▶ Hippocratic Oath, 600 BC to 11 AD.
- ▶ Greek physician, father of medicine
- ▶ “What I may see or hear in the course of treatment or even outside of the treatment in regard to the life of men...I will keep to myself..
- ▶ The beginning of medical confidentiality

First Cancer Registrar

- ▶ Florence Nightingale upgraded profession of nurse, 1820-1910
- ▶ Formerly considered prostitutes
- ▶ Insisted on careful recording of deaths and outcomes of hospitalization.

Questions

Is it immoral, illegal, or unethical:

- ▶ to park on the wrong side of the street?
- ▶ to cheat on your income taxes?
- ▶ For a CTR to embezzle money from a local organization?
- ▶ For a CTR to lie on a job application about an educational degree not related to cancer registry work?

Ethical Concerns of Other Groups

- ▶ World Health Organization—2002 launched Ethics and Health Initiative
- ▶ JACHO—1st chapter in Standards is “Ethics, Rights, and Responsibilities”
- ▶ International Medical Informatics Association (IMIA)—Code of Ethics

JACHO

- ▶ Accredited organizations must address patient rights and ethical issues....
- ▶ Raise staff awareness of ethical issues in patient care, treatment, and services
- ▶ Have policies supporting ethical decision-making.
- ▶ Employees of Cancer Registry must also be aware of these ethical considerations

IMIA Code of Ethics

- ▶ Health care is information intensive and an important commodity in marketplace
- ▶ EHR private/confidential information and basis for treatment decisions
- ▶ EHR contains data for decision making by health care facilities, governments, and other agencies.
- ▶ Need balance between ethically justified ends and otherwise appropriate means.

HIPAA, 2001

- ▶ Initially to protect health insurance between jobs—health insurance portability
- ▶ Congressional testimony presented cases of misuse of medical information so confidentiality issues included in final bill
- ▶ Banker on state health commission, searched for cancer patients with his mortgages and called in their loans.

HIPAA Privacy Rule

- ▶ Protects confidentiality of individually identifiable health information
- ▶ Addresses responsibilities of those maintaining health information
- ▶ Describes who can access the information
- ▶ Outlines process for obtaining access

USA—European Union Data Transmission

- ▶ EU Data Protection Directive of 1998
- ▶ Members not to transmit patient data to countries that don't have comparable laws of privacy protection
- ▶ USA is one of these countries.
- ▶ Threatens to cut off data exchange unless compromise can be reached
- ▶ Dept of Commerce working on a 'Safe Harbor' policy which would allow transfer of such data to USA

Kenneth Goodman

Why is Privacy so Important?

- ▶ Eli Lilly acquired PCS Health Systems to access its database of 56 million patients and encourage physicians to prescribe Lilly Products (Wall St. Journal, May 11,1995)
- ▶ Information on genetic predispositions may make it difficult to obtain insurance

Courts and Data Privacy

- ▶ Coal tar in underground tanks blamed for increase in childhood cancers
- ▶ Children, parents sued public service company and engineering firm.
- ▶ State DofPH subpoenaed for patient files
- ▶ Replied 'privileged health data'
- ▶ Ordered to list type of cancer, date of diagnosis, and patient's zip code.

Right to Know Vs. Right to Privacy

► Cancer registries:

1. should be familiar with state laws re: research participation and patient confidentiality
2. should have affiliated IRB and Research Committee to review and process data requests.
3. must establish written policies and procedures on data use and protection of privacy.

Vivien Chen

“When tempted to do anything in secret, ask yourself if you would do it in public. If you would not, be sure it is wrong.”

Jefferson

Thomas

The National Cancer Registrars Association

Professional Practice Code of Ethics

Professional Practice Code of Ethics

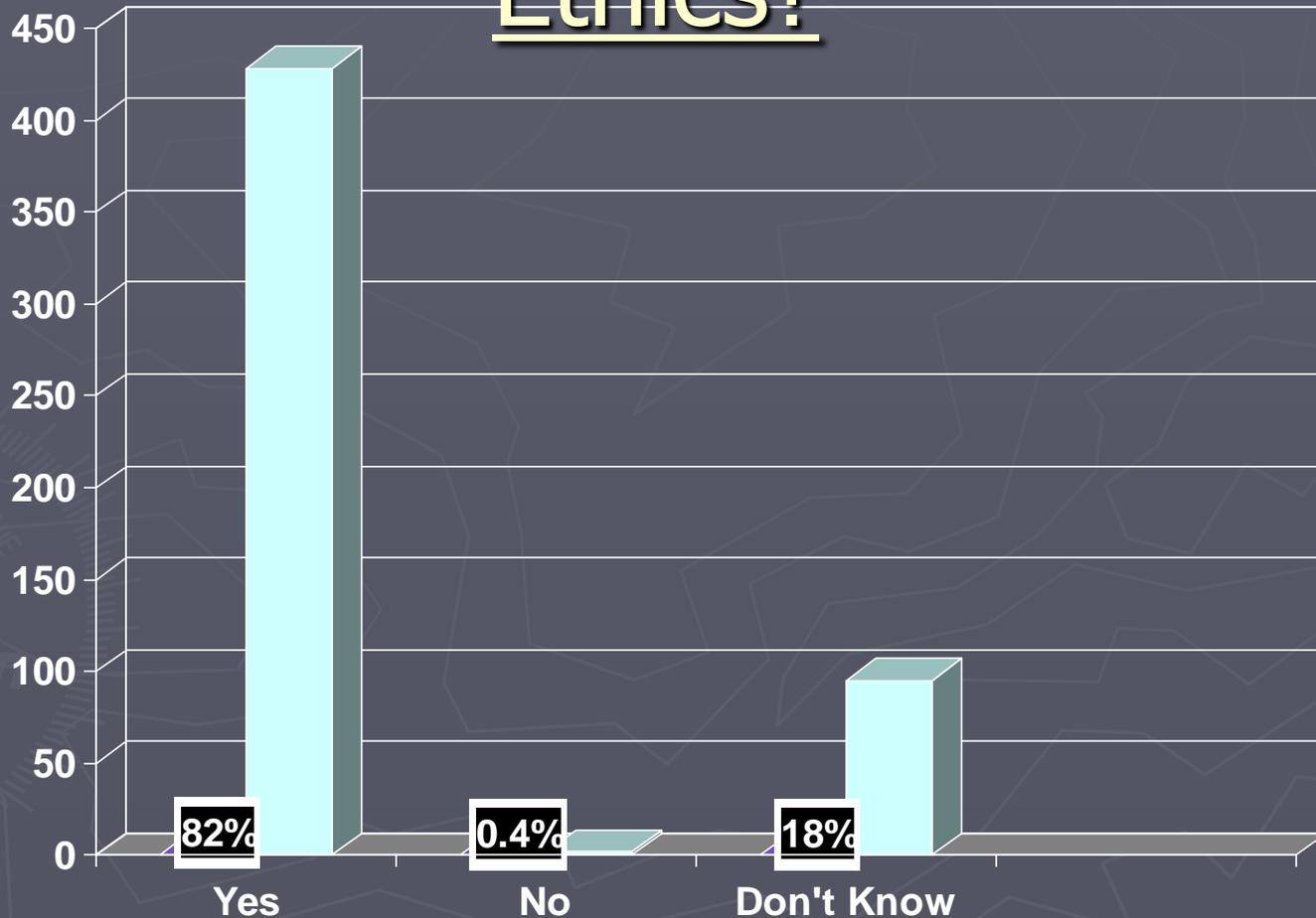
- ▶ Outlines principles of professional conduct.
 - provides members of the Association with definitive and binding guidelines of conduct.

Professional Practice Code of Ethics

- ▶ The Cancer Registrar shall maintain high standards of conduct, integrity, and fairness in all professional actions and decisions to establish and sustain an irreproachable, professional reputation
- ▶ Bring honor and dignity to oneself, the cancer registry profession, and the Association.

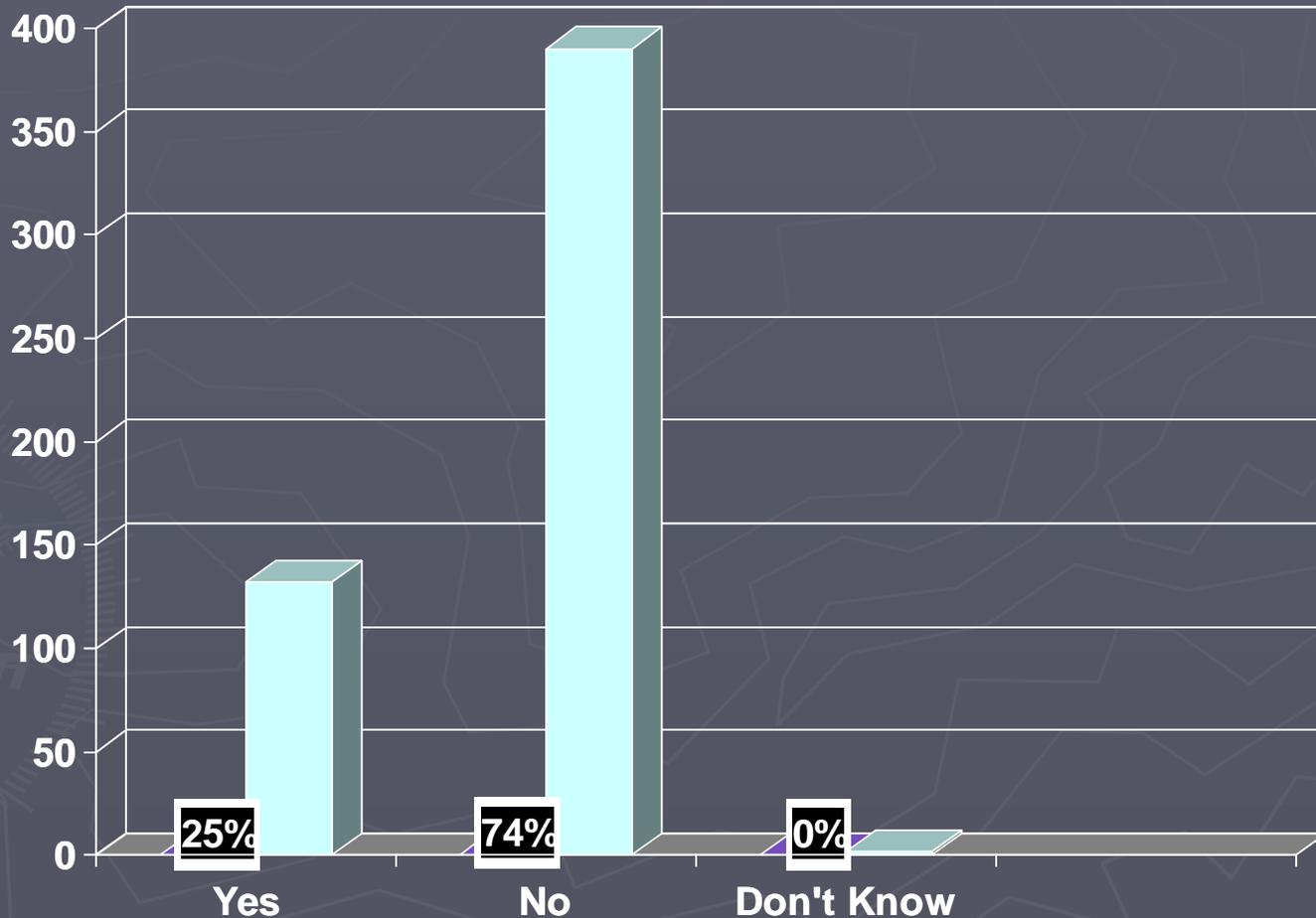
Ethics Survey Results

Does NCRA have a Code of Ethics?



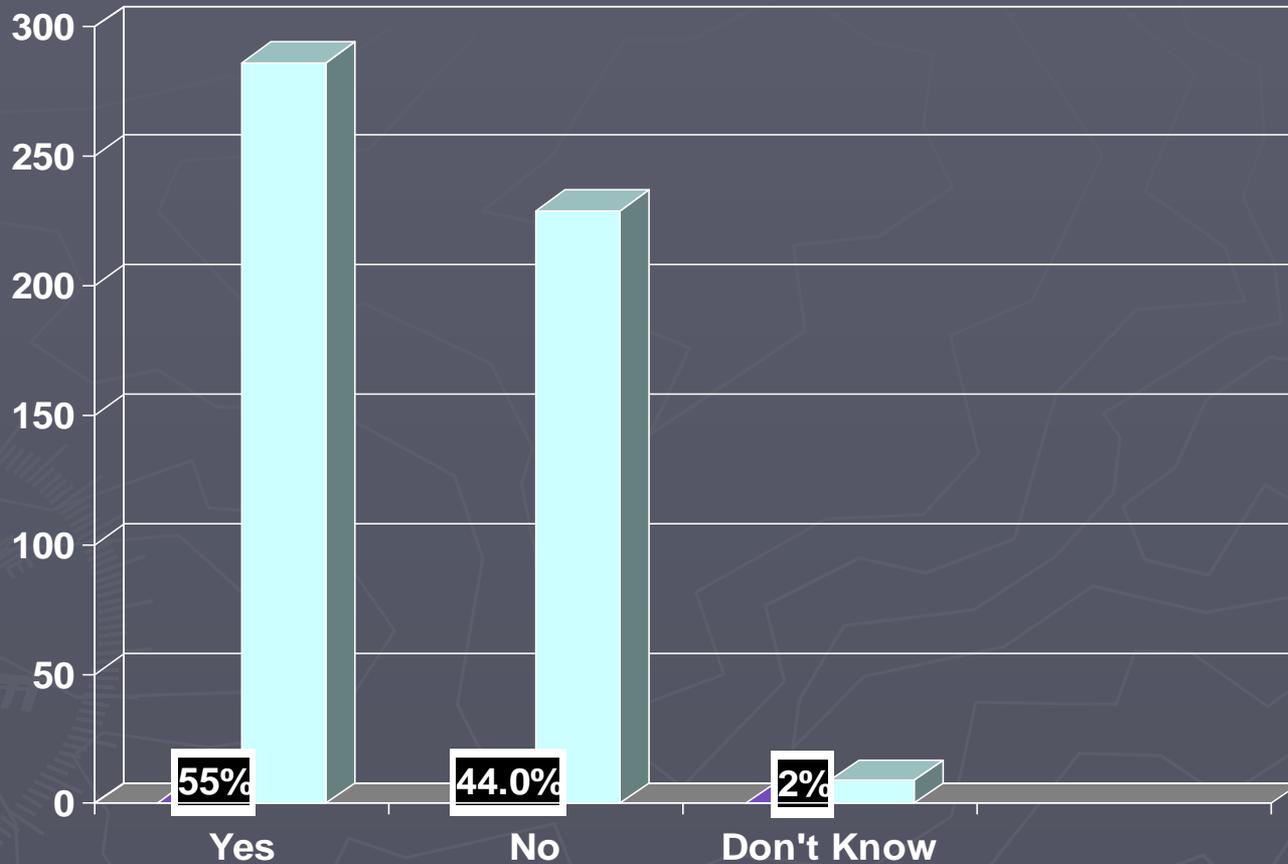
Ethics Survey Results

Have you been asked to do something you feel is professionally unethical?



Ethics Survey Results

Have you seen others do things you consider professionally unethical?



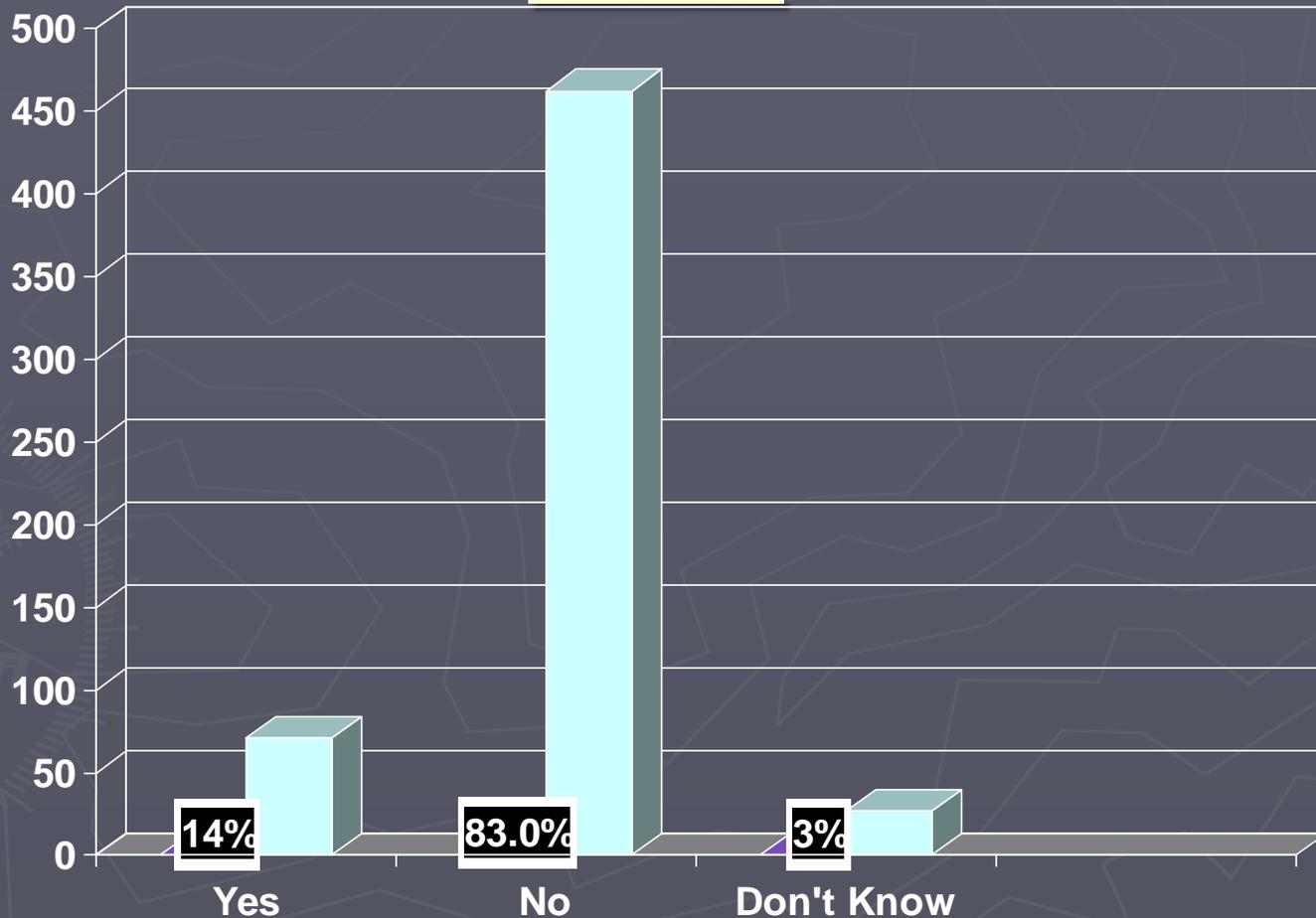
Ethics Survey Results

- ▶ Have you ever seen anyone do the following:



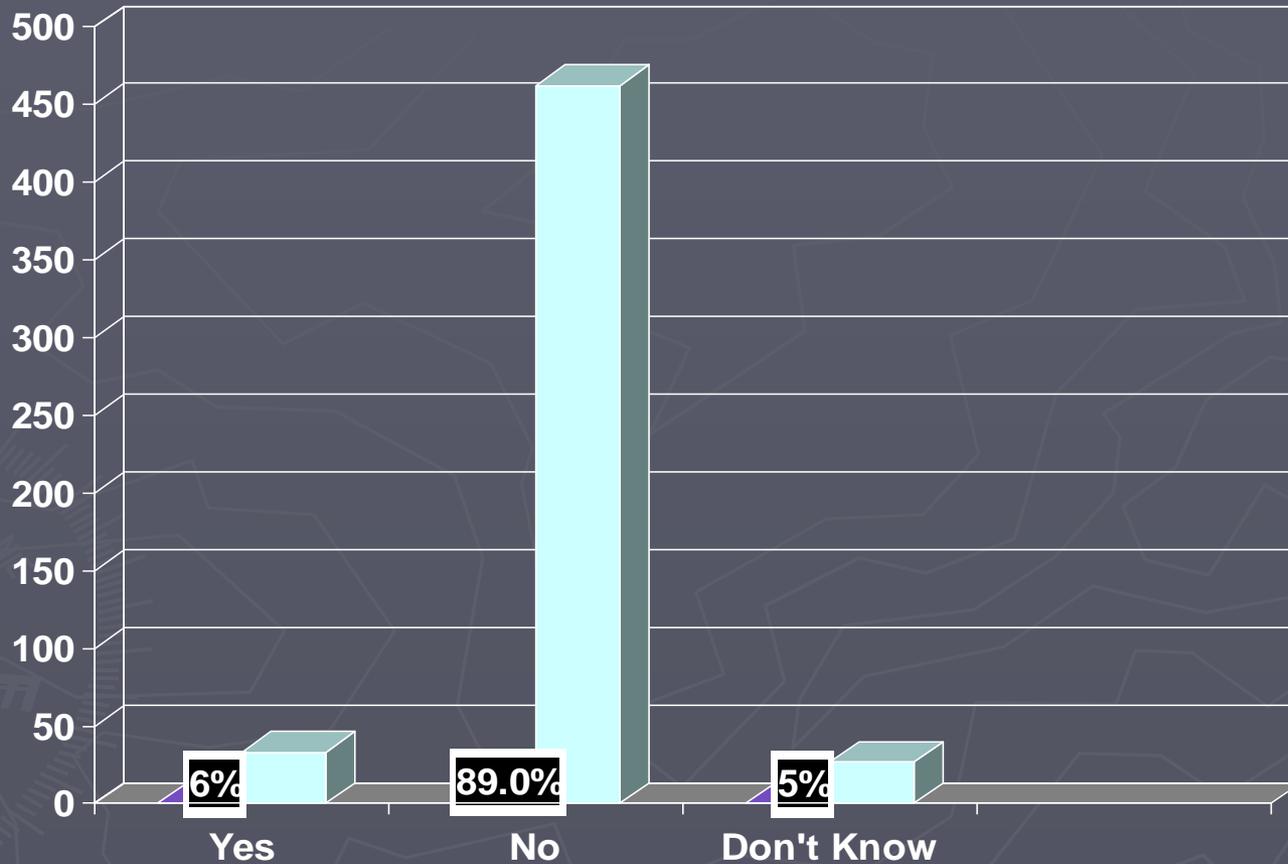
Ethics Survey Results

Using CTR credentials when they have not been earned or revoked?



Ethics Survey Results

Using CTR credentials incorrectly?



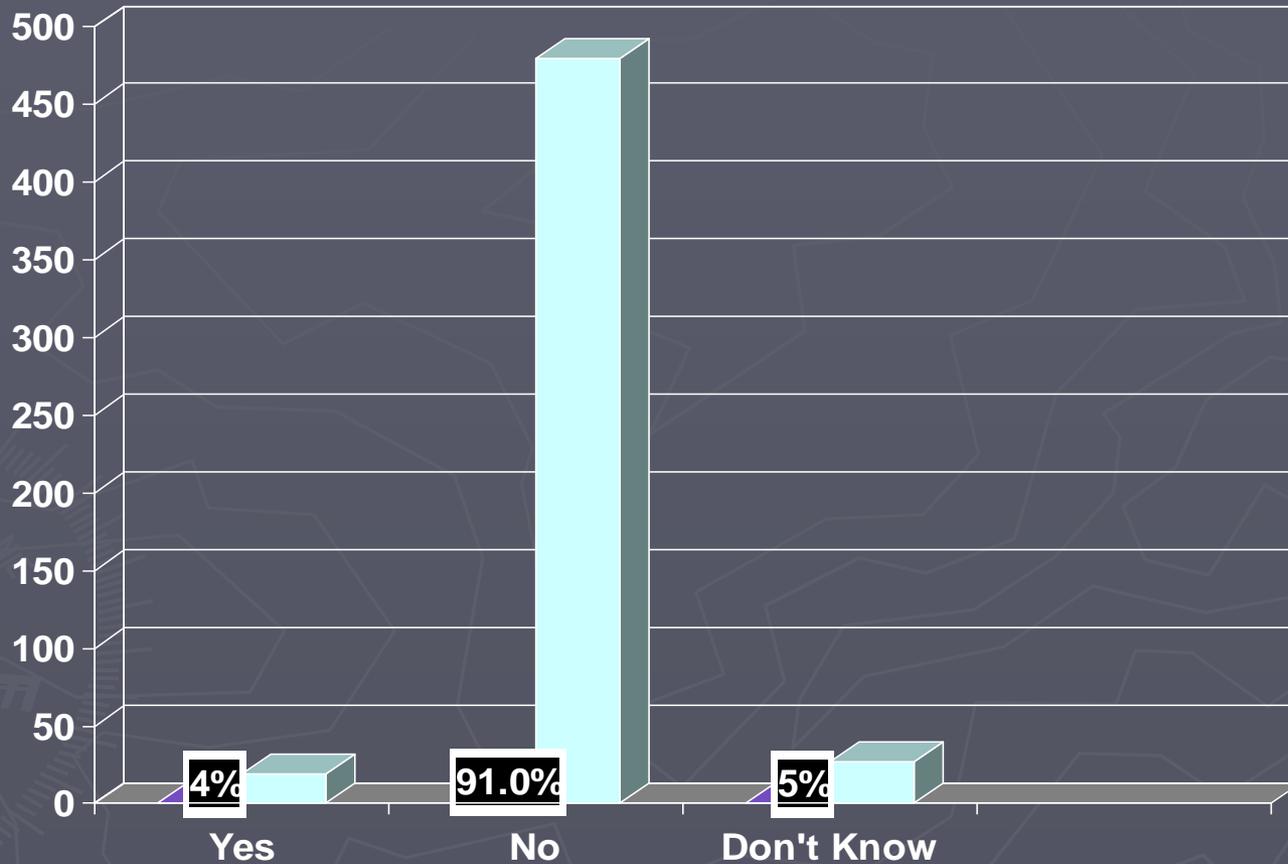
Using CTR credentials incorrectly?

▶ Examples:

- Using CTR when you do not possess the credential
 - ▶ Prior to passing the exam
 - ▶ CTR suspended or revoked

Ethics Survey Results

Deliberately misrepresenting NCRA's positions and policies?



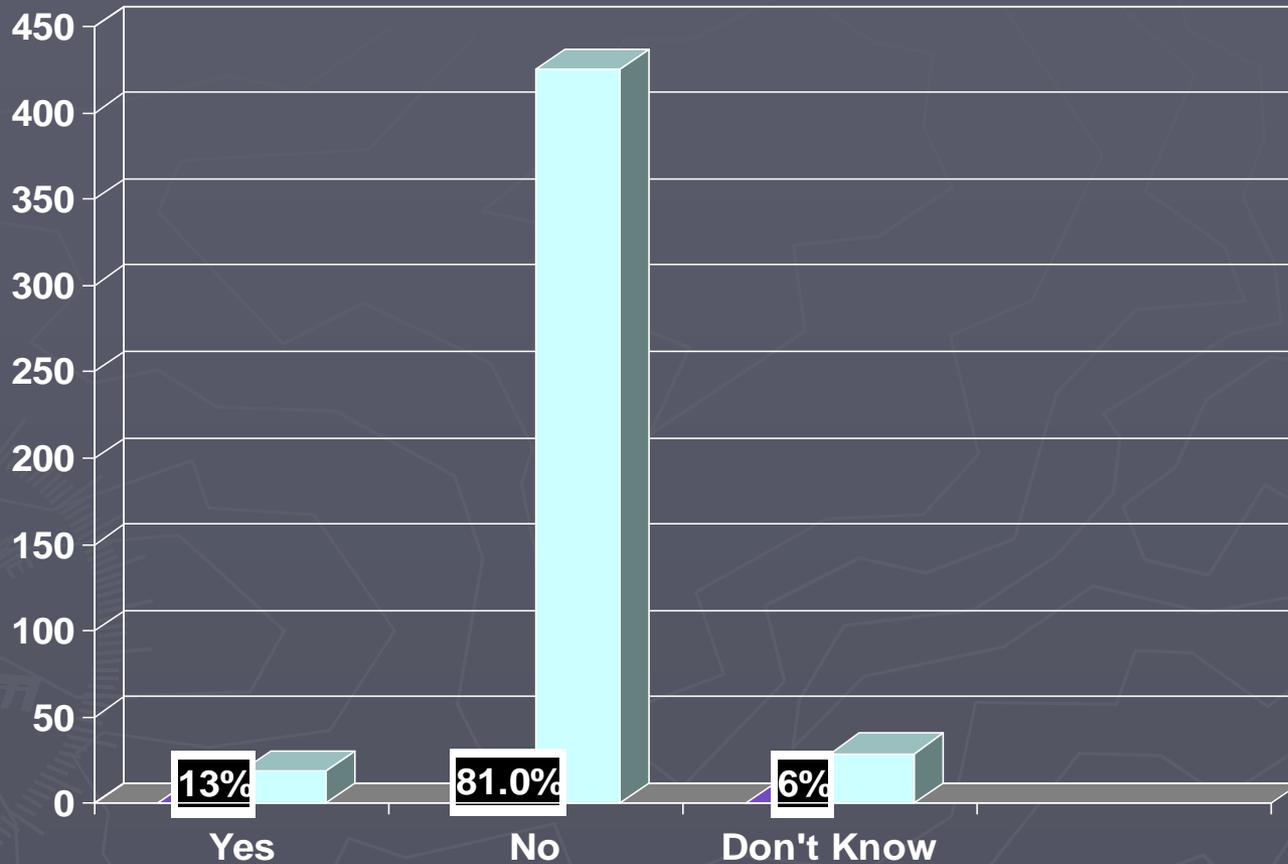
Deliberately misrepresenting NCRA's positions and policies?

► Examples:

- Representing one's own view as that of the Association or the majority of the members
- Using the NCRA logo or address on business cards and letterhead stationary

Ethics Survey Results

Not controlling patient privacy when electronically processing information, esp. when working from home?



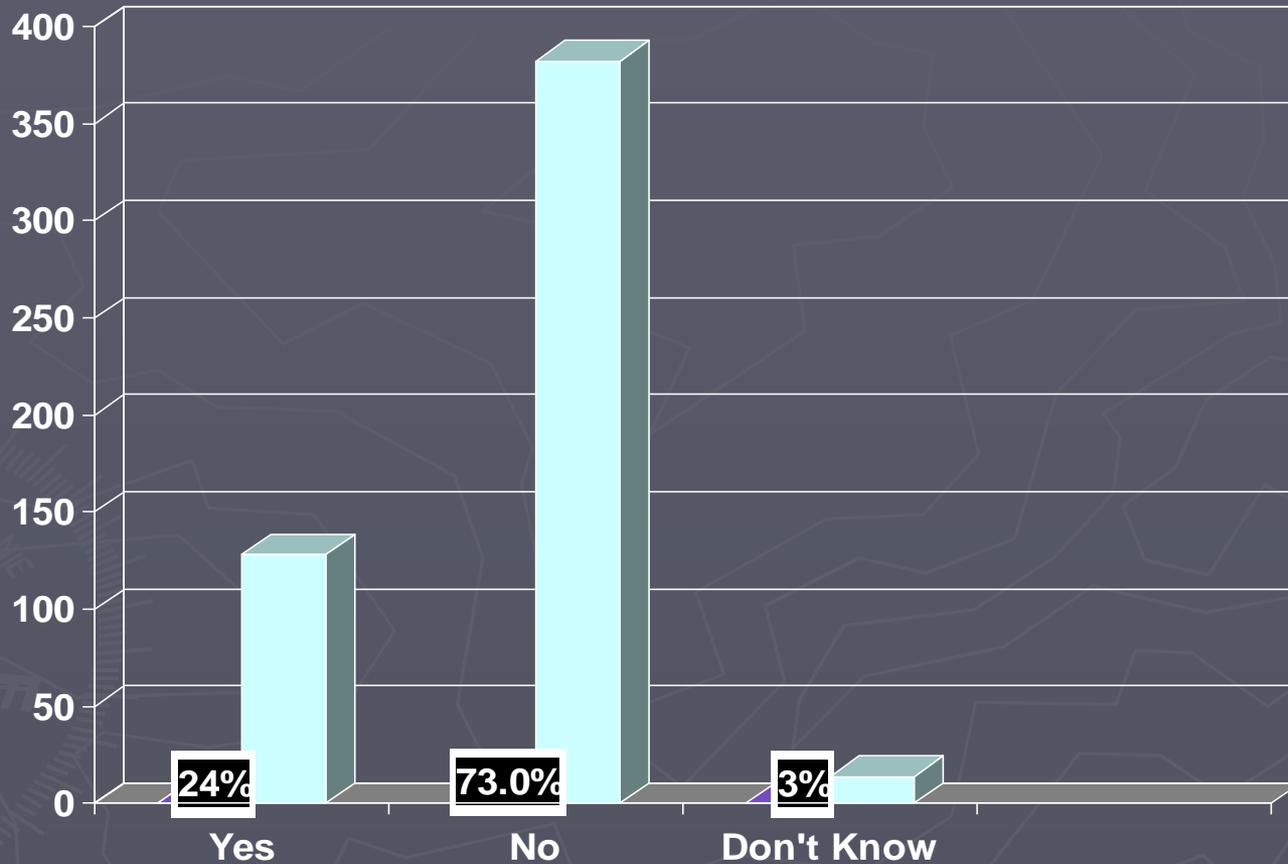
Not controlling patient privacy when electronically processing information, esp. when working from home?

► Examples:

- Not storing patients' records in a secure location, i.e., leaving patient information where others can read
- Leaving patient data on unattended computer screen
- Not properly disposing of paperwork with patient information, i.e., not shredding

Ethics Survey Results

Deliberately making up patient data (i.e., treatment, follow-up, behavior codes) to complete records on time, increase incidence rates, or follow-up rates?



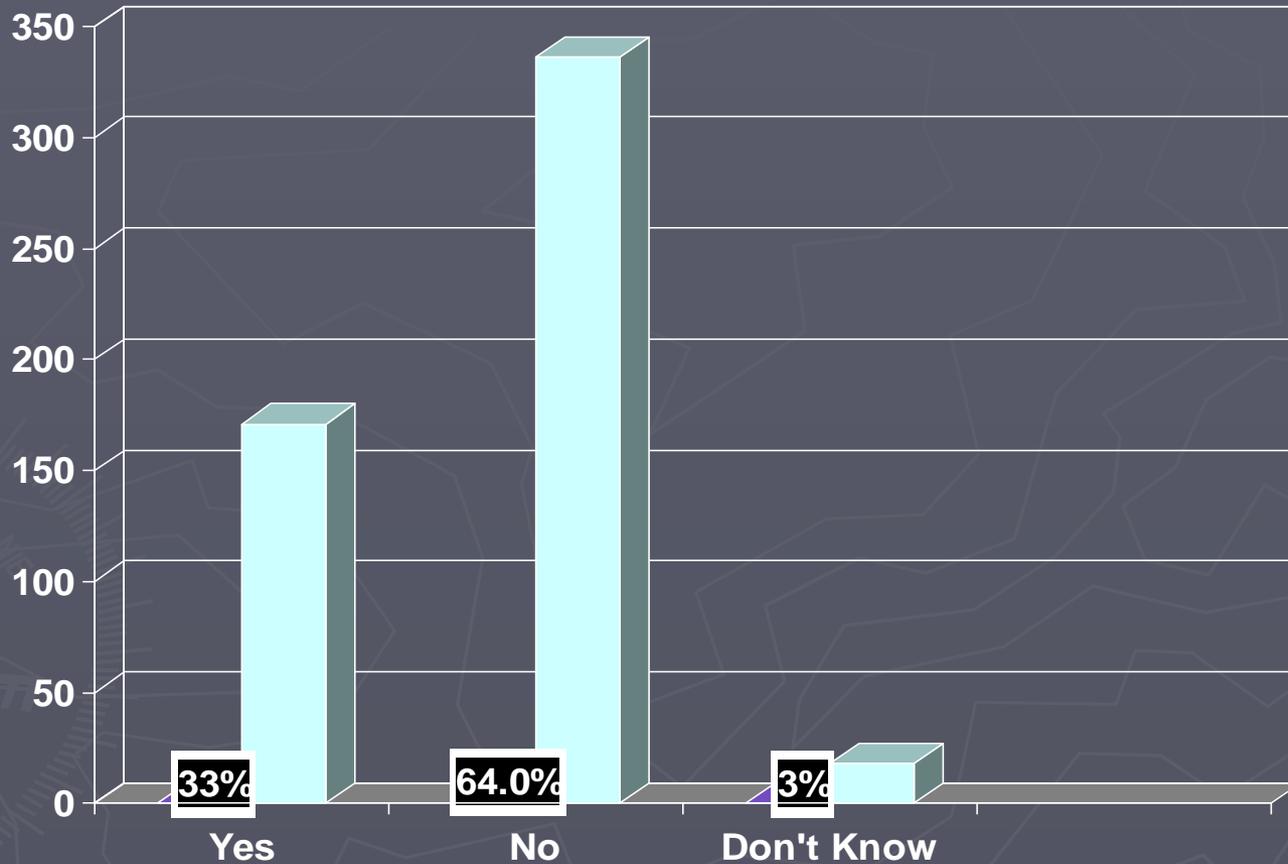
Deliberately making up patient data (i.e., treatment, follow-up, behavior codes) to complete records on time, increase incidence rates, or follow-up rates?

► **Examples:**

- Altering dates in follow-up to reflect more current follow-up or making up dates
- Changing class of case to 0 or 3 to eliminate cases from follow-up
- Changing behavior codes from malignant to non-malignant to eliminate from follow-up
- Entering bogus cases to increase incidence

Ethics Survey Results

Not rendering a truthful accounting of the status of work over which one has responsibility?



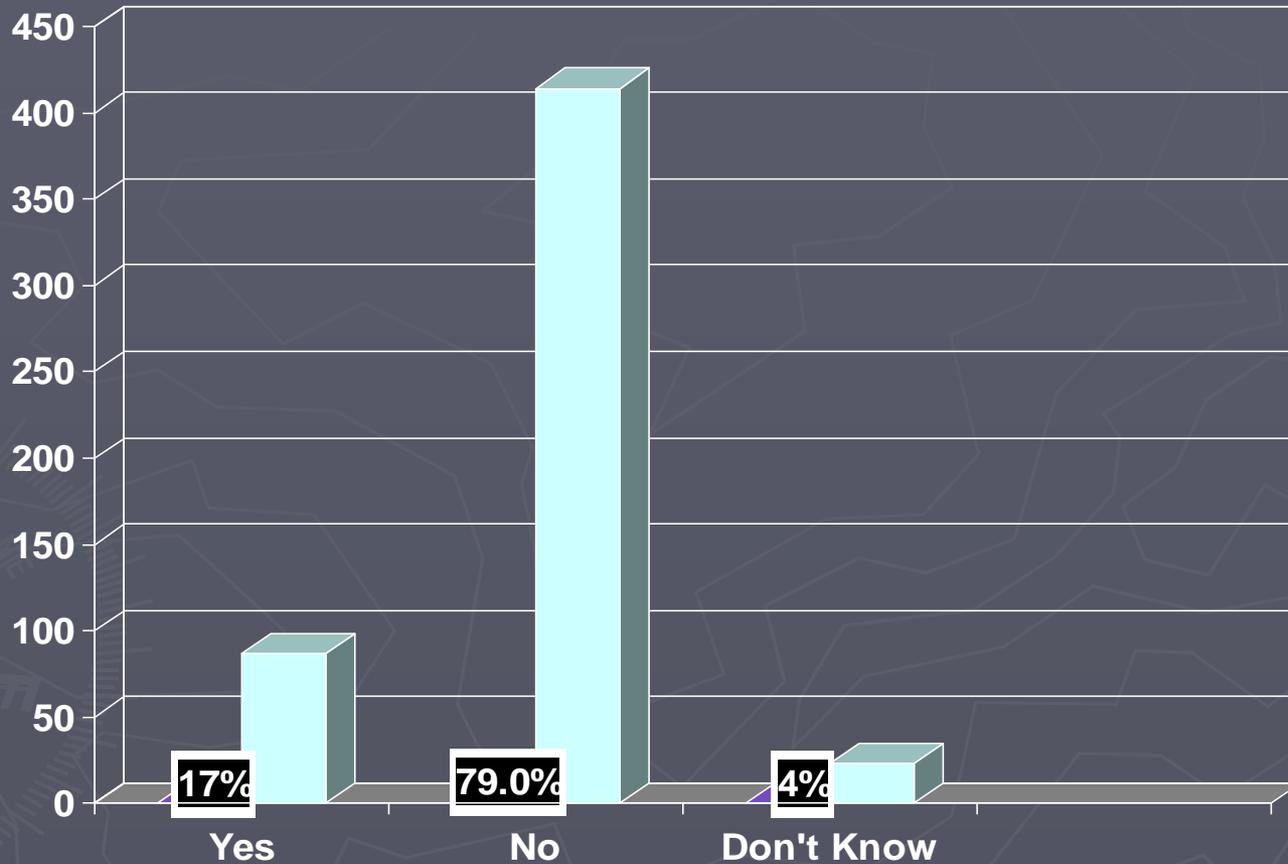
Not rendering a truthful accounting of the status of work over which one has responsibility?

▶ Examples:

- Reporting incorrect information to superiors
 - ▶ Administration
 - ▶ Cancer Committee
 - ▶ Central Registry
 - ▶ Other reporting agencies

Ethics Survey Results

Improper preparation, alteration, or suppression of medical health records or official minutes maintained as part of the facility's operation?



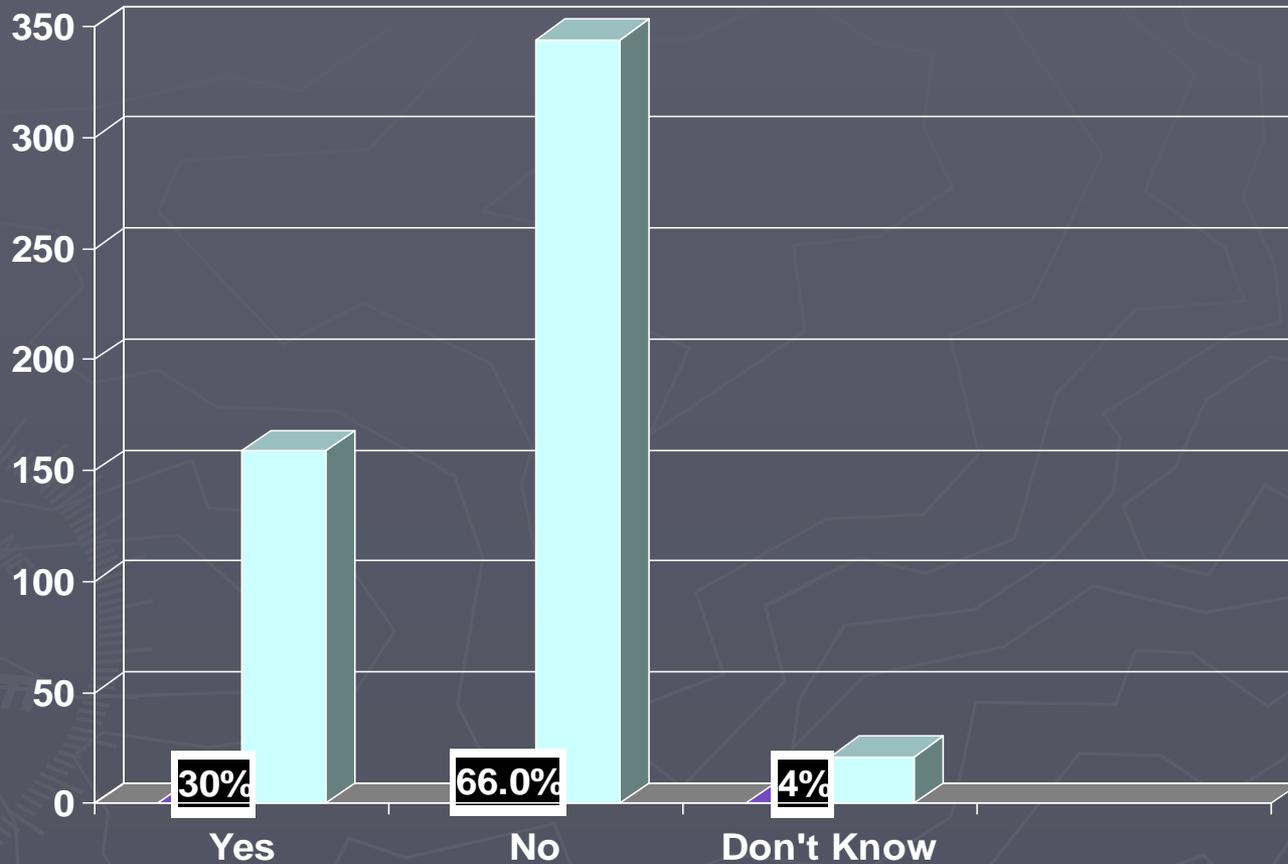
Improper preparation, alteration, or suppression of medical health records or official minutes maintained as part of the facility's operation?

► Examples:

- Creating minutes of meetings never held
- Altering contents of Cancer Committee meeting minutes
- Leaving adverse information out of meeting minutes

Ethics Survey Results

Not providing professional growth and development to those under supervision?



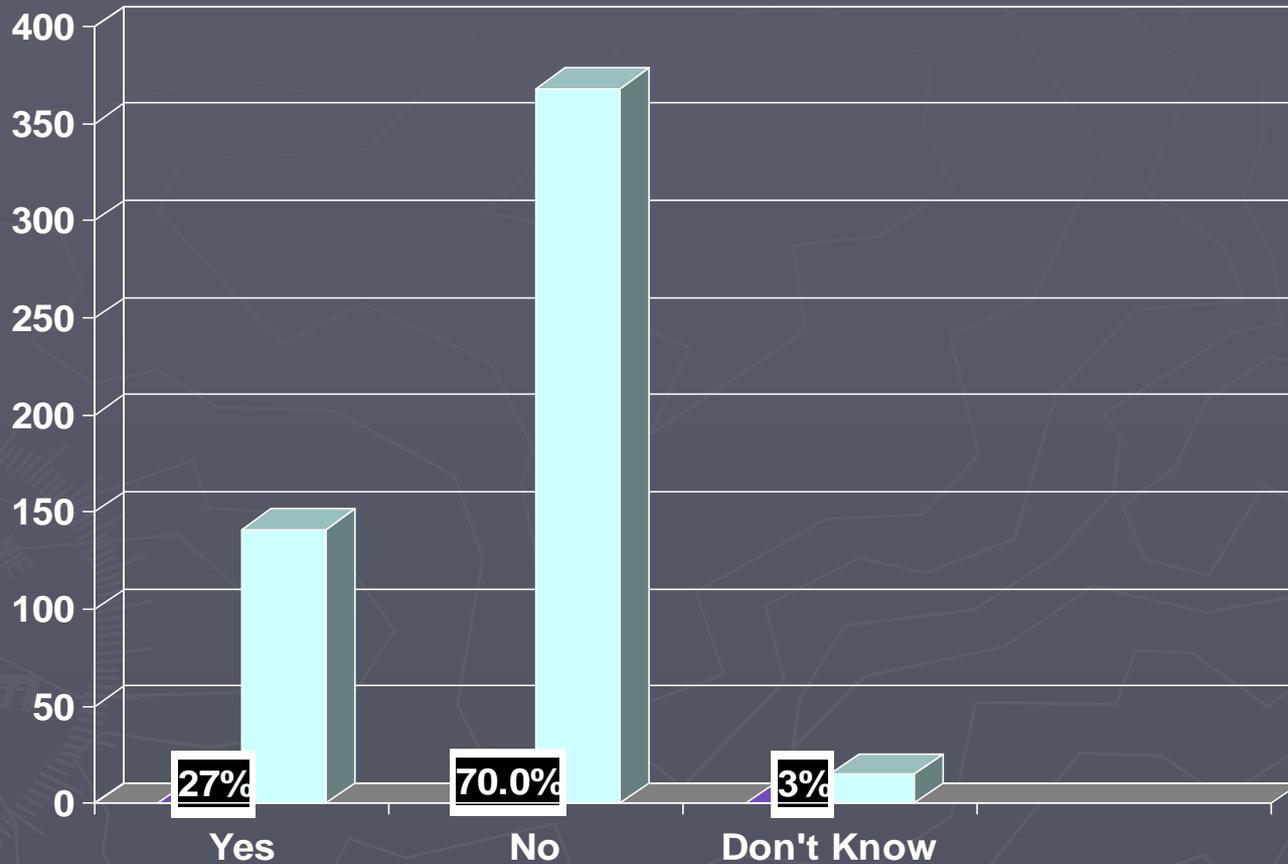
Not providing professional growth and development to those under supervision?

► Examples:

- No constructive criticism/feedback
- No educational opportunities
- No formal instruction
- No proper tools – manuals, updates, etc.
- No proper access to do the job
- No software updates

Ethics Survey Results

Walking away with manuals and/or other resource materials belonging to an employer?



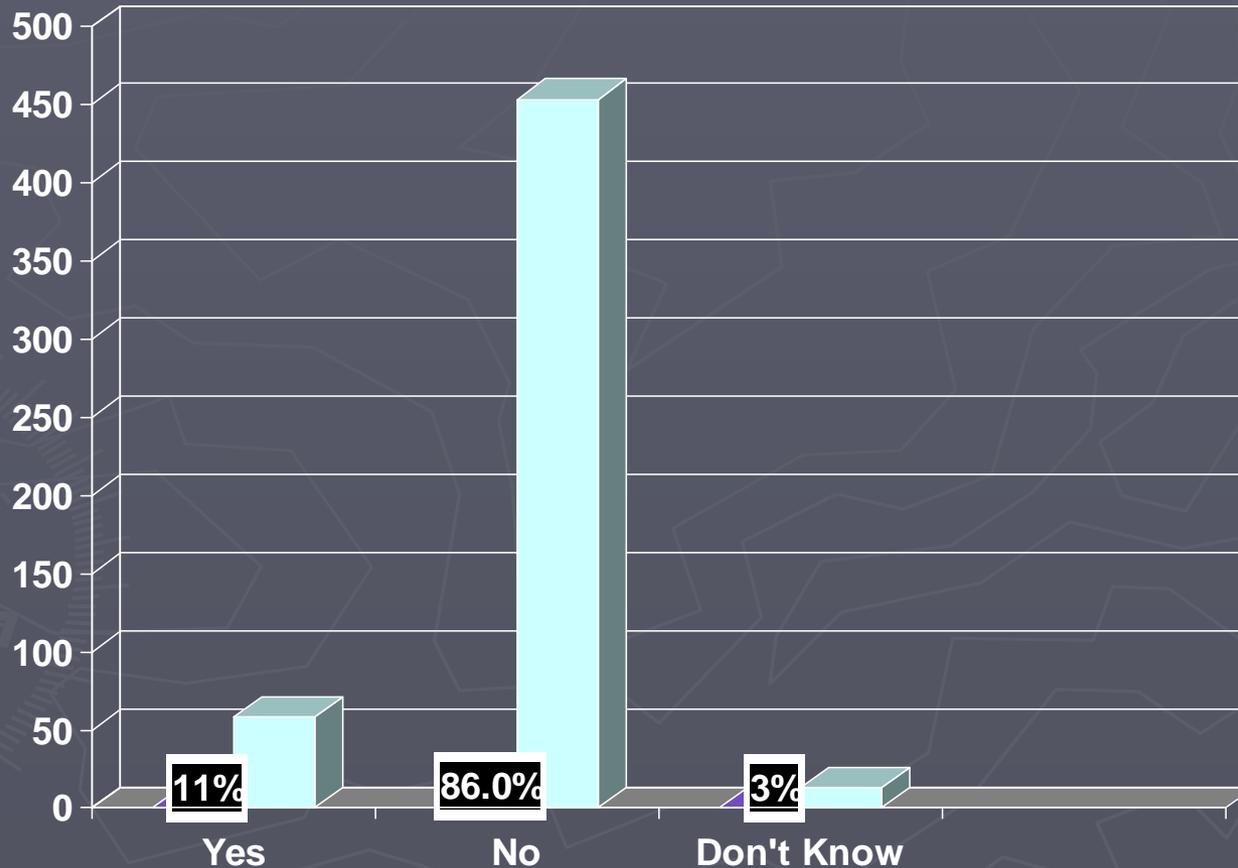
Walking away with manuals and/or other resource materials belonging to an employer?

▶ Examples:

- Taking manuals, electronic data or any other resource materials belonging to the employer
 - ▶ If you developed materials as an employee it belongs to the employer not you (ask permission prior)

Ethics Survey Results

Providing information regarding a cancer patient's diagnosis or other medical information without verifying that the person making the request is entitled to the information?



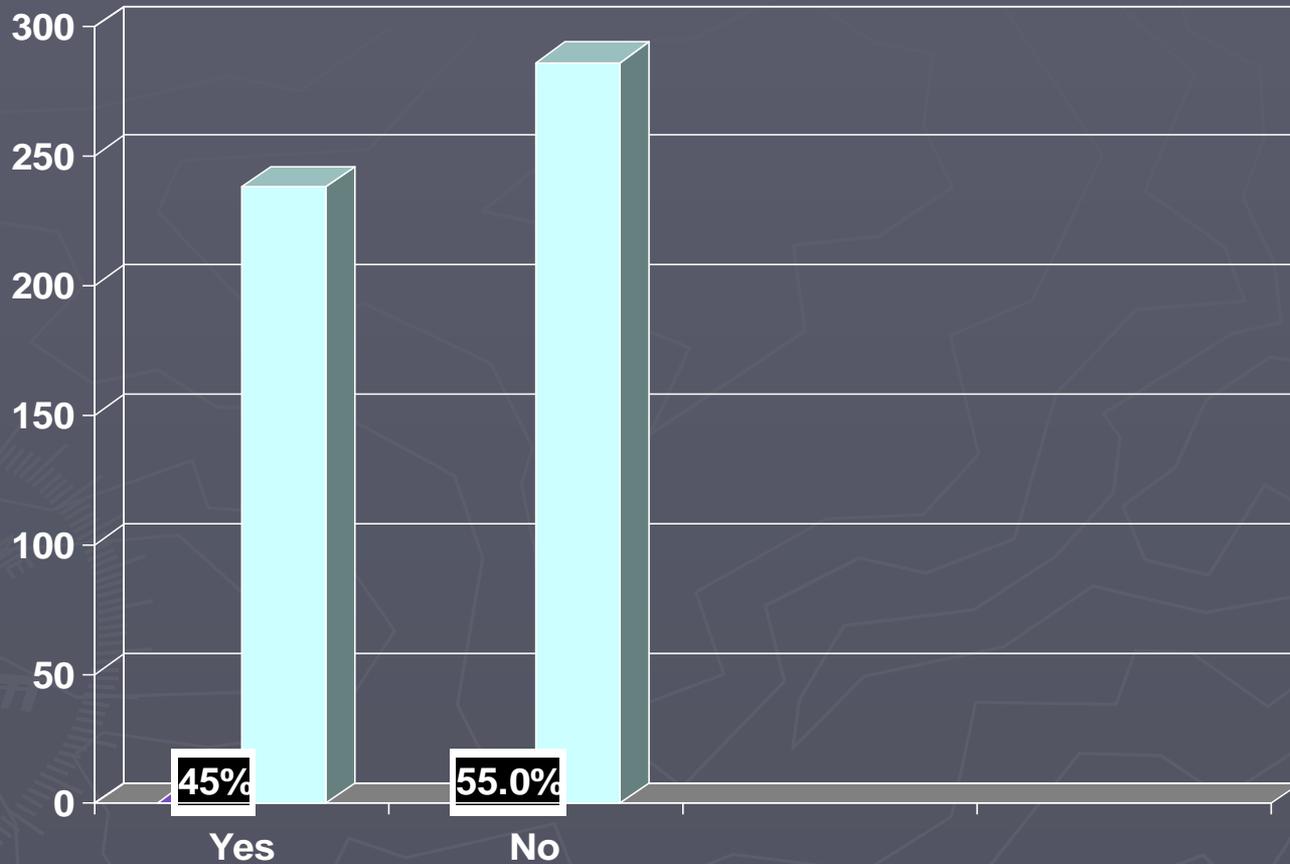
Providing information regarding a cancer patient's diagnosis or other medical information without verifying that the person making the request is entitled to the information?

▶ **Examples:**

- Know who you are talking to and who has a need to know

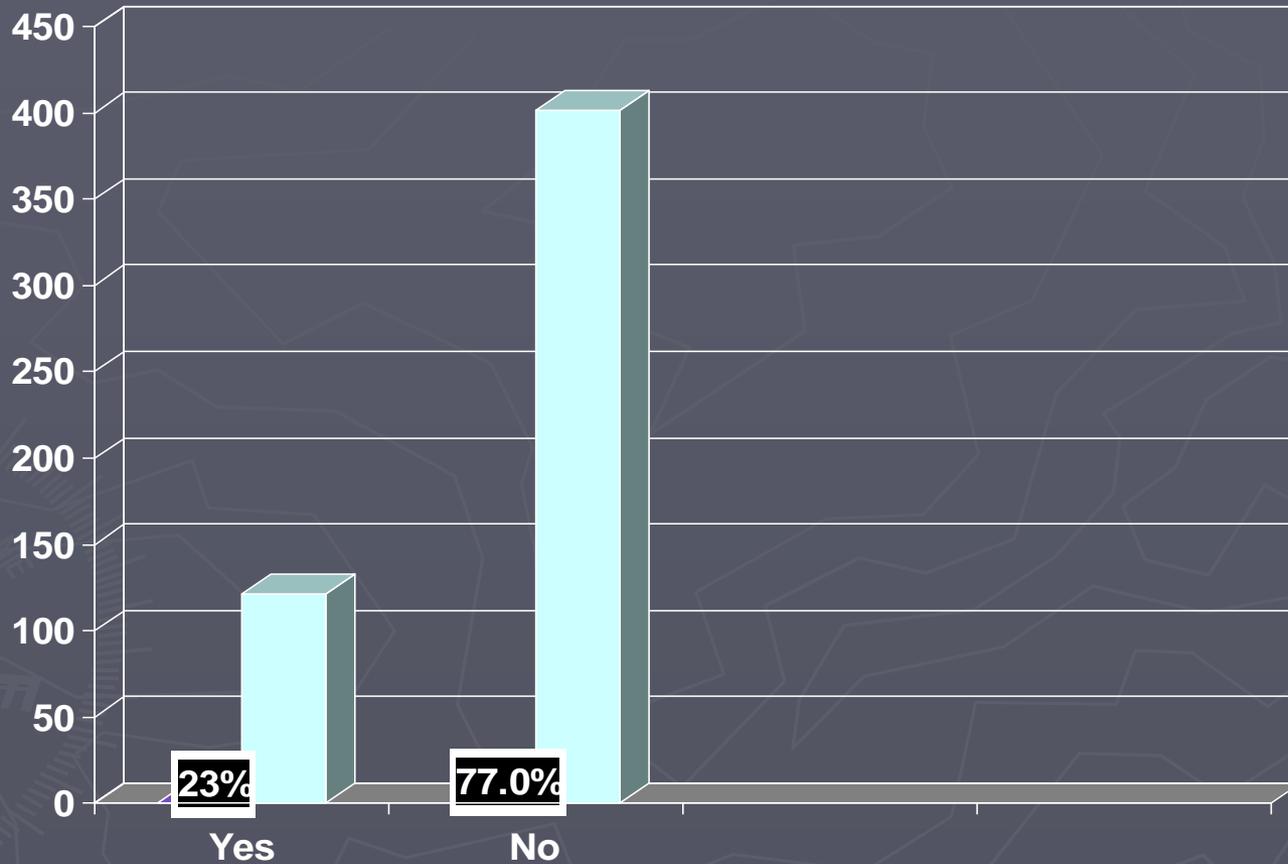
Ethics Survey Results

Have you read NCRA's Code of Ethics?



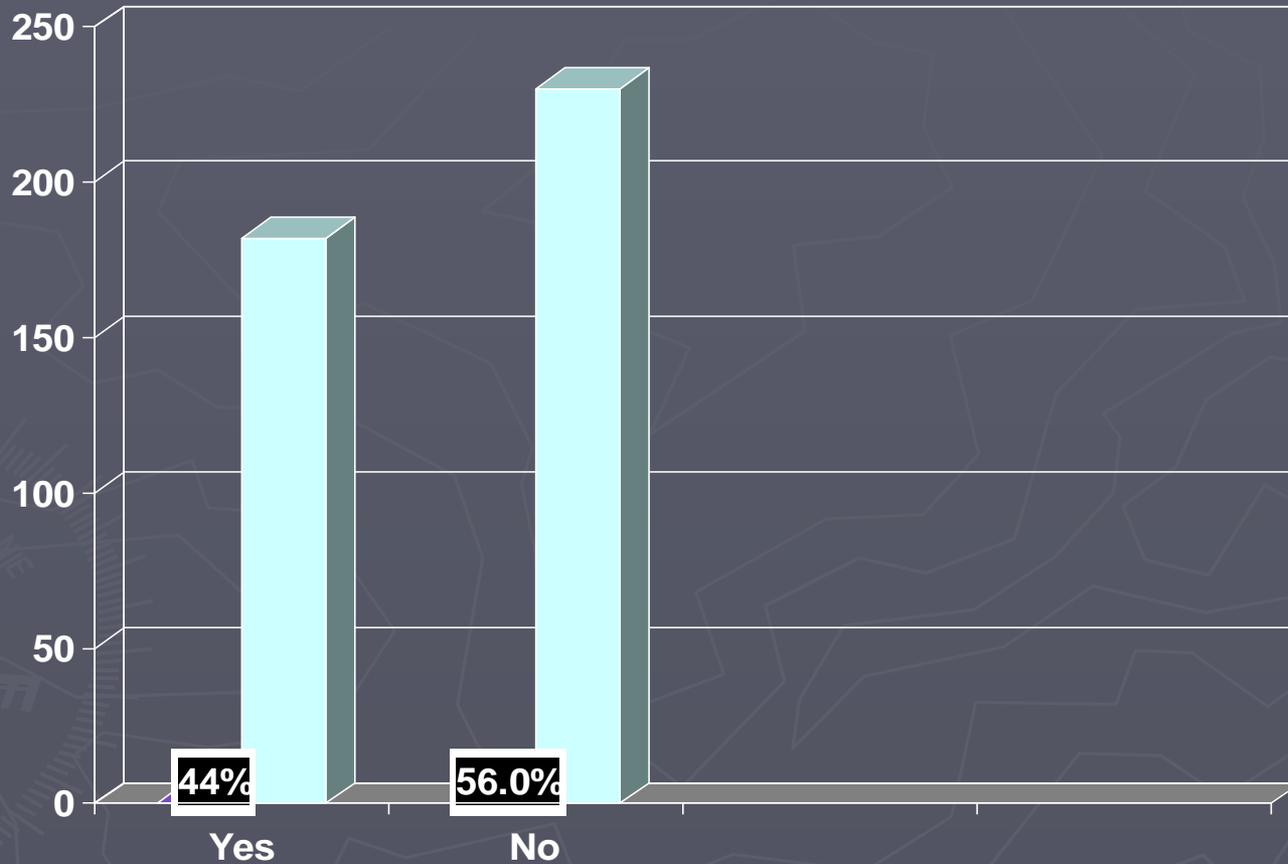
Ethics Survey Results

Have you ever accessed the Code of Ethics from NCRA's website?



Ethics Survey Results

If no, do you know how to access NCRA's Code of Ethics on the website?



NCRA's Professional Practice Code of Ethics

- ▶ <http://www.ncra-usa.org/>
- ▶ Go to the members page.

NCRA's Professional Practice Code of Ethics

► Responsibility:

- Uphold the standards of the profession by reporting to the Ethics Committee of the Association any breach of this code by fellow members of the profession.

NCRA's Professional Practice Code of Ethics

- ▶ Report a breach of the Code of Ethics or file a formal complaint by:
 - Following the guidelines found in the Ethics Committee's Policy and Procedures
 - ▶ <http://www.ncra-usa.org/members/pdfs/policyprocedure/EthicsCommittee.pdf>
 - Submitting complaints to the Ethics Committee Chair
 - ▶ Susan O'Hara, CTR
 - ▶ susanvohara@verizon.net

NCRA's Professional Practice Code of Ethics

► Questions?

